



To: House Human Services Committee
From: Jessa Barnard, Executive Director,
jbarnard@vtmd.org
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CHAPTER 4A. AMYOTROPHIC LATERAL SCLEROSIS REGISTRY

§ 171. DEFINITIONS

As used in this chapter:

- (1) “Amyotrophic lateral sclerosis” or “ALS” means a progressive neurodegenerative disease that affects nerve cells in the brain and the spinal cord.
- (2) “Health care facility” has the same meaning as in section 9432 of this title.
- (3) “Health care provider” has the same meaning as in section 9432 of this title.

§ 172. ESTABLISHMENT OF AMYOTROPHIC LATERAL SCLEROSIS REGISTRY

(a) The Commissioner shall establish a uniform statewide population-based amyotrophic lateral sclerosis registry system for the collection of information determining the incidence of amyotrophic lateral sclerosis and related data. Pursuant to 3 V.S.A. chapter 25, the Commissioner shall adopt rules necessary

to effect the purposes of this chapter, including the data to be reported and the effective date after which reporting by health care facilities and health care providers shall be required.

(b) All cases of amyotrophic lateral sclerosis diagnosed or treated in the State shall be reported to the representative of the Department of Health authorized by the Commissioner to compile the amyotrophic lateral sclerosis data, or any individual, agency, or organization designated to cooperate with that representative, in accordance with the rules adopted under subsection (a).

~~(c) The Commissioner shall establish a training program for the personnel of participating health care facilities and a quality control program for amyotrophic lateral sclerosis data. The Commissioner shall collaborate in studies with clinicians and epidemiologists and publish reports on the results of such studies.~~ The Commissioner shall cooperate with the National Institutes of Health and the Centers for Disease Control and Prevention in providing amyotrophic lateral sclerosis incidence data.

§ 173. PARTICIPATION IN PROGRAM

(a) Any health care facility or provider diagnosing or providing treatment to patients with amyotrophic lateral sclerosis shall report each case of amyotrophic lateral sclerosis diagnosed to the Commissioner or the Commissioner's authorized representative in a format and within timelines prescribed by Rule by the Commissioner, within 180 days of admission or diagnosis. If the facility fails to report in a format prescribed by the

~~Commissioner, the Commissioner's authorized representative may enter the facility, obtain the information, and report it in the appropriate format. In these cases, the facility shall reimburse the Commissioner or the authorized representative for the cost of obtaining and reporting the information.~~

~~(b) Any health care provider diagnosing or providing treatment to patients with amyotrophic lateral sclerosis shall report each case to the Commissioner or the Commissioner's authorized representative within 180 days of diagnosis.~~

~~(c) All health care facilities and health care providers who provide diagnostic or treatment services to patients with amyotrophic lateral sclerosis shall report to the Commissioner any further demographic, diagnostic, or treatment information requested by the Commissioner concerning any person now or formerly receiving services. Additionally, the Commissioner or the Commissioner's authorized representative shall have physical access to all records that would identify cases of amyotrophic lateral sclerosis or would establish characteristics of the amyotrophic lateral sclerosis, treatment of the amyotrophic lateral sclerosis, or medical status of any identified patient with amyotrophic lateral sclerosis.~~

§ 174. CONFIDENTIALITY

[[remained of bill unchanged]]